Letters to the Editor

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Cancer Genetics and Insurance

To the Editor:

Rodriguez-Bigas et al. (1998) made a commendable effort to ask 1,000 of a total of 5,178 U.S. health, disability, and life insurance companies about their policies (and conditions) for insuring patients and asymptomatic carriers of the gene for autosomal dominant hereditary nonpolyposis colorectal cancer (HNPCC). The low response rate (7.7%) and the heterogeneity of the insurance companies' attitudes (which ranged from acceptance to rejection of people with these types of risks) do not warrant the authors' optimistic conclusions that "the majority of health, life, and disability insurance providers with an opinion would be willing to sell insurance to both HNPCC gene carriers and at-risk individuals" (Rodriguez-Bigas et al. 1998, p. 737). In The Netherlands (population 15,000,000), the health and life insurance companies expressed the intention to prolong a moratorium on the use of genetic data to control access to life insurance, at the same time that legislative efforts were proposed to reduce the risks of genetic discrimination in access to health insurance and jobs (Committee on Genetic Screening 1994, pp. 86–87). In industrial countries, there is a strong tendency to reduce risk sharing in health insurance and social security systems. This tendency will cause an even greater increase in insurance companies' awareness of risk differentiation based on outcomes of genetic tests (Pokorski 1995; Bodmer 1996).

In view of these nearly global developments, appropriate counseling on the social effects of taking a presymptomatic test for a late-onset genetic disease, such as a cancer syndrome or a neurodegenerative disorder, has become a very delicate matter for clinical geneticists (The Ad Hoc Committee on Genetic Testing/Insurance Issues 1995). The silence of the majority of the insurance companies in the U.S. study by Rodriguez-Bigas et al. (1998) reflects the general neglect of this subject in discussions between the governments of the major economic countries and the regulators of the international insurance and underwriters system.

Families with these genetic risks may become burdened by the unacceptable financial risks of the "wait and see" attitude of the health and life insurance system and the policy makers responsible for these regulations. In Great Britain, life insurers recently started demanding genetic-test results (Wilkie 1998).

Geneticists usually are held responsible for potential adverse socioeconomic effects of genetic testing, by making already foreseeable genetic risks more precise. However, from the onset of presymptomatic testing, society and policy makers have been informed, by the genetics community, of the need to formulate regulations based on fairness and the prevention of genetic discrimination (The Ad Hoc Committee on Genetic Testing/Insurance Issues 1995).

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